



Considering “Patient” Perspectives for Advancing Patient Registries

AzTransNet Policy Development Retreat
Wednesday June 4, 2008
Scottsdale, Arizona

Sponsored by the Arizona Biomedical Research Commission and Arizona
Hospital and Healthcare Association



Our Perspective and Our Role

Barbara B. Kavanagh, MSW, Founder and President,
The Arizona Myeloma Network, AzMN

Kay Kays, Patient Advocates IN Research (PAIR)
Co-Founder: AzMN Tissue Donor Awareness Project,
TDAP™



Overview of the Patient Perspective

- The Patient Perspective, Kay Kays
 - Recommendations: A Collaborative Approach
- Case Study: The Arizona Myeloma Network ... A Patient / Family Perspective, Barbara Kavanagh
 - The Tissue Donor Awareness Project, TDAP™ Model



Kay Kays/Patient Overview

Overview questions asked for comment:

To: Patients

Patient Advocates

Patient Advocacy
Organizations

- Do you feel patient registries could be used to increase cancer clinical trial accrual?
- What motivation would a patient have to participate in a cancer patient registry?
- What patient barriers need to be addressed?



Kay Kays/ Patient Perspective

- Pancreatic Cancer Survivor (4 time/14 years)
- Enrolled in 2 cancer registries

St. Joseph's Hospital & Medical Center
John Hopkins Pancreatic Familiar Registry

- Motivation to enroll into cancer registries
 - Clinical trial stress
 - Advance research
- Patient barriers toward registries
 - Contact timing
 - Clinical trial obstacles
 - Confidentiality



Az. Patient Advocate Perspective

- Cancer registries to advance clinical trial accrual could be beneficial, but with the proper informed consent. I am not sure what the motivational factors might be...definitely less patient stress in finding a trial, but probably needs a study.
Patient confidentiality is a definite barrier. Patients need protection and this electronic age, firm enforceable, and guarantees to their privacy.

- Karen L. Lewkowitz, BSN, RN (retired)
National Breast Cancer Coalition, Lead Field Coordinator-AZ



Az Patient Advocate Perspective

- I am unsure that using cancer registries to advance cancer clinical trial research would be the best approach. It might help, but I also see patient barriers as mail clutter / overload, patient contact inappropriate or unwanted, and the need to have personal contact with the patient. Advocacy organizations or local medical personnel, who already have the patient's trust, should be used more productively in reaching out to patients concerning clinical trials. Many cancer trials recruit relapsed patients and the time frame is very short once you relapse. In remission, many don't want to hear about what if I relapse. Local medical professionals need to be a better job of reaching out to patient advocates who can spread the word about how to seek trial information on local trials available, and how to even apply for a trial.

- Joan Bald, Lymphoma Patient and Advocate
- Founding & Past President, Lymphoma Research Foundation



Az. Patient Advocate Perspective

- The development and use of an African American registry to collect clinical research data could be beneficial. However, I don't think the cancer registries are the tool that will solve the problem of getting African Americans to volunteer for clinical trial participation. Having no trust in the system, this faith-based culture needs a voice and a steady presence in the community, not a recruitment notice in the mail.

- Sharon Jaycox, MHA
- Liaison to Special Populations for the
Bureau of Chronic Disease Prevention and Control &
Outreach Coordinator for Comprehensive Cancer Control
Arizona Department of Health Services



Az. Patient Advocate Perspective

- It appears that Asian Pacific Islanders have the tendency to less likely participate in a clinical trial due to lack of awareness (especially people with low education), problem with the medication like side effects, language barrier, lack of cultural and social support, family members against the research, physicians do not talk or refer clients to clinical trials, and fear of experimentation. I believe all these factors would be considered in participating in a cancer registry as with the clinical trials.

Yen Nguyen, MPH, Outreach Coordinator
Asian Pacific Community in Action (APCA)



Arizona Patient Advocate Perspective

- We've been focused on this area for a couple of years now, and are still working it. Delighted you are into this area!!

- Marcia K. Horn
President and CEO
International Cancer Advocacy Network (ICAN)



National Patient Advocacy

- We certainly do believe that access to clinical trials is of the utmost importance to patients. Most cancer registries exist for the purposes of studying the disease, but anything that can be done to increase patients' access to clinical trials is a step in the right direction. I would think that the most significant barrier for pancreatic cancer patients would be that they want to get into a trial or treatment right away. I suppose that means time or urgency is the barrier.

Michele Duff, Dir. Patient/Liaison Services & Medical Affairs
Pancreatic Cancer Action Network



National Patient Advocacy

- The NCI / NIH cancer biomedical Informatics grid (caBIG™) objective is to connect the people, institutions, and data in the cancer community through caBIG™ and working with various groups in moving this forward is one of the major goals. Patient confidentiality is of utmost importance in this initiative. Assuring standards of compliance in security for the data and the people who access it is the focus of the Data Security and Intellectual Property workspace of the project.

■ Diane Paul, caBIG™ Patient Advocate



National Patient Advocacy

- This project would hold more value if an extensive patient survey was done and you knew that patients would be willing to participate. Research patient advocates need to be locally utilized ...studies have shown they are the first line for information by patients.
 - Paula Kim, President & CEO
 - Translating Research Across Communities



Conclusions on Considering Patient Perspectives

- Important role for Patient Advocates for outreach, awareness building and information sharing
- Consider implementing a Patient Survey
- Network with local/national advocacy groups for patient awareness/education
 - Example of collaboration with caBIG TM for cancer research
- Address the need for cultural specific registries
- Ensure confidentiality



Arizona Myeloma Network

- **THE ARIZONA MYELOMA NETWORK (AzMN) IS A 501(C)(3) cancer charity, founded in June 2004 by Barbara Kavanagh, cancer patient advocate.**
- **What is Myeloma? Multiple Myeloma is a complex and often misdiagnosed cancer of bone marrow plasma cells that attacks and destroys the bone. The cause is unknown and there are over 1500 new cases of myeloma diagnosed each month.**
- **AzMN is made up of patients, families, caregivers, healthcare professionals, volunteers and others concerned about Myeloma.**

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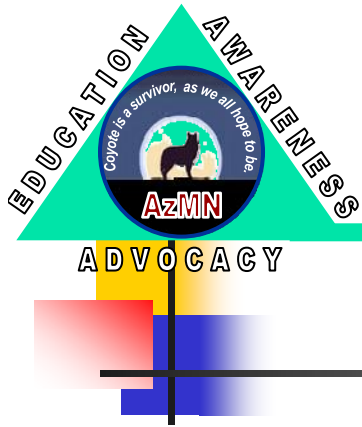
www.azmyelomanetwork.org



Arizona Myeloma Network

■ Programs:

- Annual "Living with Myeloma Conference"
- Free cancer awareness programs for the community
- Bi monthly newsletter
- Website information
- Annual fall AzMN Charity Golf Tournament, Honoring Myeloma patients and Researchers.
- Annual Diamondbacks / AzMN Charity Corner Game
- "Cancer is Everybody's Business": Annual Luncheon for Science, Business and Cancer Leaders and Advocates.

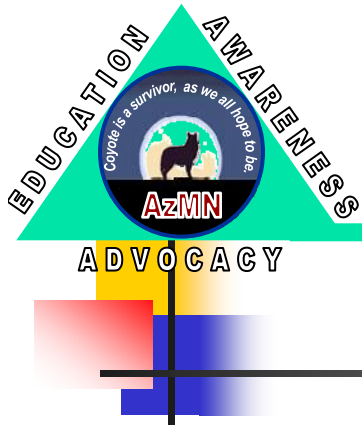


Arizona Myeloma Network

Cancer Community Awareness The Tissue Donor Awareness Project (TDAP)

Barbara Kavanagh, Director

Kay Kays, Deputy Director

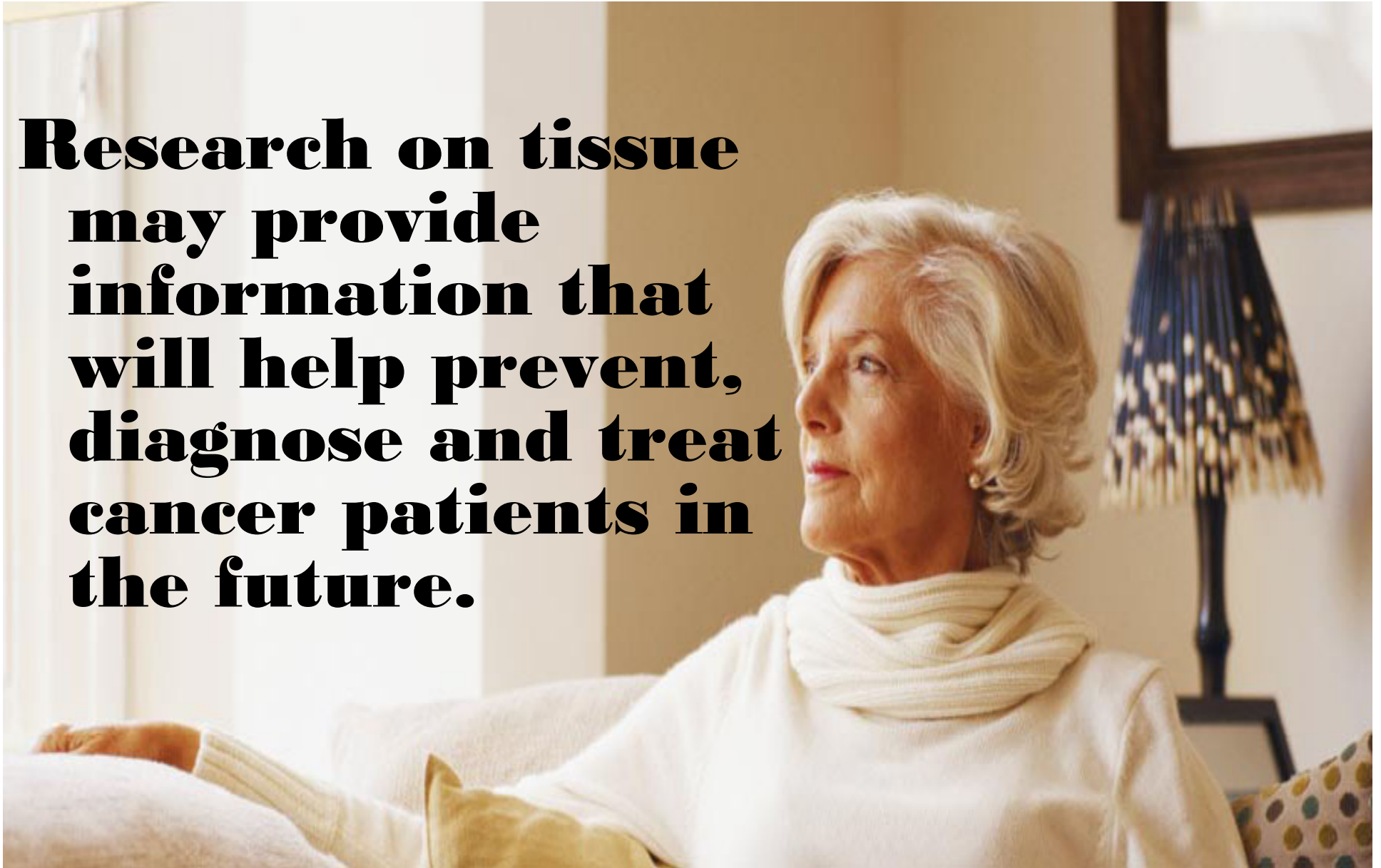


Arizona Myeloma Network

TDAP™ Program:

- **Tissue Donor Awareness Project (TDAP™) was a CCP ADHS grant (HR754127) award**
- **Cancer Community TDAP™ in 3 Arizona communities: Phoenix, Prescott and Tucson**
- **"Tissue Issue" – community outreach raising awareness about the need for tissue donation, research, better treatment, diagnosis, prevention and cure**
- **Listen to concerns regarding donation**
- **Define barriers preventing donation**

**Research on tissue
may provide
information that
will help prevent,
diagnose and treat
cancer patients in
the future.**

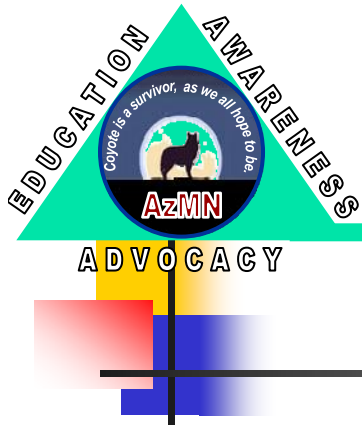


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Kinds of tissue used in research



- Residual or extra tissue taken for the patient's diagnosis and treatment.
- Tissue taken specifically for research purposes, e.g., blood.
- Excess normal tissue.



Arizona Myeloma Network

Our Vision

- **Expand our community/research collaborations**
- **Continue to deliver myeloma education and advocacy programs**
- **Develop additional TDAP™ Programs to expand tissue awareness.**
- **Design Cancer Patient Advocacy Training (CPAT™) – a cancer research advocacy program.**
- **Seek diverse funding and support to promote and deliver tissue awareness programs to the under-served throughout AZ**
- **Continue to bring together a network of cancer patients and their families, science, and businesses working towards a common goal:**

Earlier diagnosis, Better treatment and a CURE!

www.azmyelomanetwork.org